

## **A QUALITATIVE STUDY OF THE IMPACT OF CARING FOR A PERSON WITH URINARY INCONTINENCE**

### Hypothesis / aims of study

As the population ages, a growing number of people will act as caregivers for family members who have long-term chronic diseases. Incontinence in older people is strongly associated with physical dependency, poor mobility and cognitive impairment. Approximately 10-20% of women and 7-10% of men over the age of 65 living at home experience urinary incontinence and a census of Leicestershire homes and hospitals found that over 40% of older people in long-term care were regularly incontinent of urine. Whereas it is well recognised that urinary incontinence has a negative impact on the quality of life of the sufferer, little is known about the impact of this distressing condition on the primary caregiver and the role, requirements and impact on the carer's quality of life has not been the focus of much research. Where research has been conducted [1] it was found that care giving is a financial burden and also led to decreased intimacy, a perceived role change and a change in sleeping circumstances. Caregivers were also more prone to depression and for many spouses embarrassment significantly increased the chance of caregiver and recipient isolation [2]. Given the increasing pressure on older people to remain in their own homes, the impact on carers may become increasingly important. The aims of this study were to explore the role, feelings and requirements of the caregiver of a patient with urinary incontinence using qualitative methods, document the effect on quality of life by means of a modified Kings Health Questionnaire, document the effect on caregiver burden by means of the Zarit Caregiver Burden Questionnaire.

### Study design, materials and methods

A literature review to facilitate data gathering and suggest themes was performed. All patients registered on the Camden PCT continence database were mailed and carers invited to take part in semi-structured interviews. A qualitative method using grounded theory was used. Interviews were recorded, transcribed, analysed for emerging themes and coded, using two researchers to cross reference data. Each interview generated themes which were then used for subsequent interviews until saturation was reached. Zarit Caregiver Burden Interview Score (ZBI) was collected, a higher score is associated with increased burden.

### Results

A purposive sample of 8 carers was interviewed. Mean ZBI was 40/88. Three major themes were extracted, coded as foundations, adaptations and outcomes (figure). The foundations were loyalty, love, dedication, gradual evolution and acceptance. The adaptations were information gathering and coping strategies. Outcomes were poor sleep, social isolation, financial constraints, poor health, frustration and changing relationship. Outcomes were strongly influenced by education and good communication with professionals. Carers preferred to look after loved ones at home.

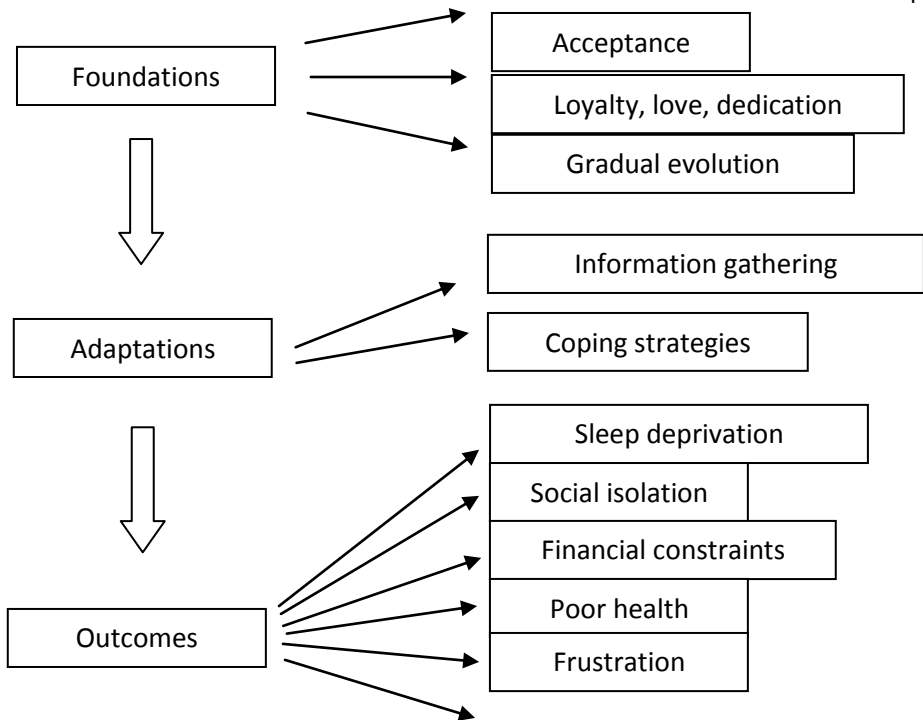
### Interpretation of results

A ZBI cut-off score ranging from 24-26 has significant predictive validity for identifying caregivers at risk for depression [3]. This study confirms that burden can lead to poor health in caregivers. Improvement in communication at both primary and secondary care level along with formation of local carer groups was identified as an important factor likely to lead to reduced burden. Burden was strongly influenced by education, appropriate advice and good communication with professionals. Carers preferred to look after loved ones at home.

### Concluding message

Simple strategies have a positive impact on caregiver burden.

Themes and foundations of factors related to carer burden associated with the care of a spouse with urinary incontinence



References

1. J. Adv Nurs 2003 Jun;42(6):607-16
2. Nurs Times 2004 Jan 13-19;100(2):46-9
3. Aging Ment Health. 2006 Mar;10(2):107-11

<b>Specify source of funding or grant</b>	<b>Departmental research funding</b>
<b>Is this a clinical trial?</b>	<b>No</b>
<b>What were the subjects in the study?</b>	<b>HUMAN</b>
<b>Was this study approved by an ethics committee?</b>	<b>Yes</b>
<b>Specify Name of Ethics Committee</b>	<b>Camden PCT REC</b>
<b>Was the Declaration of Helsinki followed?</b>	<b>Yes</b>
<b>Was informed consent obtained from the patients?</b>	<b>Yes</b>